Testimony of George Hosey Education Committee Public Hearing March 5, 2012

H.B. 5348 AN ACT CONCERNING SCHOOL NURSES AND SCHOOL MEDICAL ADVISORS

Senator Stillman, Representative Fleischmann, and members of the Education Committee, for the record my name is George Hosey of Ledyard, and I am here to testify in support of HB 5348.

I appreciate this opportunity to offer testimony and ask for a change that I feel is needed in regards to the self testing of blood glucose by students as is currently directed by school medical advisors and school nurses.

In April of last year, our son Anthony was diagnosed with Type 1 Diabetes. Since then we have learned a great deal about not only the disease, but also the obstacles and prejudices faced by diabetic children in Connecticut. Many people are not aware of the day-to-day workings of type 1 diabetes, so I would like to provide some background information:

- There is no known cure for Type 1 diabetes (also known as juvenile diabetes or "early onset" diabetes). Unlike Type 2 diabetes, it can not be controlled with diet and/or exercise.
- Type 1 diabetics produce little or no insulin naturally and must take it by some form of injection to keep their blood sugars from becoming dangerously high.
- Type 1 diabetics must check their blood sugar levels numerous times throughout the day to determine their insulin dosages and ensure they are in a "safe" range of blood sugar levels. Because they are receiving insulin externally, they are at risk of any error, overdosing etc, that could drive their blood sugar level dangerously low.
- Low blood sugar levels left unchecked can lead quickly to a diabetic lapsing into unconsciousness, coma, or even death. (...like the famous Sunny von Bulow case some years ago)
- The treatment for low blood sugar, obviously, is sugar. However, if the diabetic is unconscious/unresponsive, and thus can not swallow sugar-containing food or drink, the treatment is Glucagon an injectable hormone that raises blood sugar levels.

Though we live in the 21st century, in a world governed by the Americans with Disabilities Act and other protective legislation, we were shocked by the obstacles placed in the way of our efforts to allow our son to manage his diabetes in his school. First we were informed that Anthony could not return to school without an approved "emergency care plan". The plan, as dictated by the school nurse, required that Anthony test his blood sugar levels ONLY in the nurse's office. We found that unacceptable as we believed Anthony should be able to test wherever and whenever

he needed to in school. No agreement could be reached, so my wife or I had to go to the school **several times a day, every day** to test Anthony ourselves. During the summer, we educated ourselves in the law of the land and current practices with regard to diabetic children in schools. We returned for this school year armed with this knowledge, but to no avail. The school nurse would not budge on her requirements to limit where Anthony could test, to "evaluate" him before allowing self-testing at all (despite our possessing a written medical order from the Head of Pediatric Endocrinology at Hasbro Hospital), and continued to vaguely cite "policy" and "OSHA regs" as the reasons though neither school district policy nor OSHA regulations actually prohibited self testing in any area of school.

Since then, personnel changes have been made at the school, and that portion of the issue has been resolved. However, though Anthony's issues are resolved – for the moment – a number of questions remain – what prevents this from happening to Anthony again as he moves up from Elementary School to Middle School to High School? What prevents this from happening to other children (and their parents) throughout the state if their school nurses or administrators are unaware of, or unwilling to follow, the latest practices in juvenile diabetes management in school? The answer, of course, is bullet-proof legislation on the side of the children. As it stands today, Connecticut General Statutes are anything but. Regarding blood sugar level checking in schools, Connecticut General Statutes are very limited:

Sec. 10-220j. Blood glucose self-testing by children. Guidelines. (a) No local or regional board of education may prohibit blood glucose self-testing by children with diabetes who have a written order from a physician or an advanced practice registered nurse stating the need and the capability of such child to conduct self-testing.

(b) The Commissioner of Education, in consultation with the Commissioner of Public Health, shall develop guidelines for policies and practices with respect to blood glucose self-testing by children pursuant to subsection (a) of this section. Such guidelines shall not be construed as regulations within the scope of chapter 54.

While this statute is well-intentioned, it is clearly not sufficient. The law needs to be bolstered to allow these children to self-test anywhere in school at any time they need to. Children with diabetes, who could be suffering from potentially dangerous low blood sugar, should never be made to walk all the way to a nurse's office or some other designated location. Depending on the size and layout of a given school, this location could be several minutes walk each way from the child's classroom. (In my son's case, the distance from classroom to nurse's office is over 500 feet.) In addition to the safety aspect, there is also the matter of lost classroom instruction time. If a child is forced to leave their classroom, be it for five, ten, 15 minutes or longer each time, they miss a considerable amount of the lessons being taught, and subsequently fall behind their class. Blood glucose self-testing is safe, simple, quick,

and poses no threat to anyone else in the classroom. It is also a necessary part of any Juvenile Diabetes sufferer's learning process in terms of appropriately managing their condition.

Furthermore, Connecticut General Statutes currently do not allow for anyone other than the school nurse to administer potentially life-saving glucagon in school

Sec. 10-212a:

In the absence of a licensed nurse, only principals and teachers who have been properly trained may administer medications to students. Principals and teachers may administer oral, topical, or inhalant medications. Injectable medications may be administered by a principal or teacher only to a student with a medically diagnosed allergic condition which may require prompt treatment to protect the student against serious harm or death. Investigational drugs may not be administered by principals or teachers.

As you can see, injectables may be administered by non-medical personnel to protect the student against harm or death only in the case of a "diagnosed allergic condition". Diabetes is not an allergic condition, but is no less dangerous to those who suffer from it. Clearly, the law needs to include mention of non-allergic conditions such as diabetes.

Approximately one in 400 children in the US have been diagnosed with diabetes, and sadly, this number is increasing rapidly. Children with diabetes already carry a significant burden. To require them to leave their classrooms and miss instruction time for a medically necessary blood test is both unsafe and unfair. To fail to protect their safety during the school day is unconscionable. I ask that the Committee keep all of this in mind as it considers H.B. 5348.

Thank you.

George and Karen Hosey Ledyard CT